

# Maintaining our food choices

In response to the article published in the December 2010 edition regarding the endorsement of food at 20ppm, we received a number of emails and letters. Most of the responses were very positive however a couple where not. Two of the responses received have been printed below.

This is a complex issue which has been on The Coeliac Society's agenda (both at a national and state level) for some years. The decision, as outlined in the article in the December magazine, was made on the best available advice from our expert Coeliac Gastroenterologists in Australia. We are not aware of any doctor or Coeliac Society in the world advocating a stricter standard than 20ppm.

It is important to remember that gluten levels have not changed. For the last twenty years those with coeliac disease in Australia have been safely consuming food with gluten levels up to 20-30ppm. The only thing that has changed is the sensitivity of the testing procedure.

## Bureaucratic nit picking

I have just finished reading the December 2010 edition of 'The Australian Coeliac'. Once again it is packed with vital information and news.

It re-confirmed my long held view that one of the best decisions I ever made was the decision to join The Coeliac Society. Please pass on my heartfelt thanks to Hugh Sheardown and Graham Price and all those who have tried to get the ACCC to abandon bureaucratic nit picking and urged them to adopt the internationally accepted standard for defining 'gluten free'.

The scientific advancement in the understanding of coeliac disease that has come about with the financial and practical support of The Coeliac Society has improved my life and for that I will be eternally grateful.

I will contact my Federal Member of Parliament to add my voice to

the call for science to have priority over bureaucratic niceties. I won't fool myself in to thinking that I or my Federal Member will be able to gain any more traction than the voices of reason from The Coeliac Society but it will give me some satisfaction to know I have tried.

Thank you

*David Rees / Biloela Qld*

## Sold out to commercial interests

I am appalled that The Coeliac Society has apparently sold out to commercial interests. It is also making decisions with the members' intellectual property, the society's gluten free logo without any serious consultation with members. Australia with the active lobbying of The Coeliac Society has been a world leader in the elimination of gluten or the clear labelling of food if it contains gluten. We have now made a great leap backwards.

Australia in recent years has used technology to ensure we have safe food and should continue to do so. The Coeliac Society by lowering our standards and playing with phrases like "no detectable gluten" is working against the interests of its members. Cheaper food that is contaminated with gluten and deceptively labelled is likely to be the outcome of the changes the society has already implemented, without consultation with its members.

Gluten Free is Gluten Free, it is not a low level of gluten; it means, no gluten. The Australian Competition and Consumer Commission (ACCC) clearly understands that Gluten Free, is Free from Gluten, with no ambiguity. Products that are not gluten free will harm coeliacs. This is understood by the ACCC, but apparently not The Coeliac Society.

The Society has been a fantastic support organisation for us coeliacs, but the article on page 31 of your last issue and the "Word from the President" on page 5 is way off the mark. I and many other coeliacs do not believe any gluten in our diet is acceptable. Gluten is poison to coeliacs. There is no doubt that

any gluten in our diet will damage the digestive system of a coeliac. Therefore, we should be avoiding gluten at all times. It is the right of coeliacs to enjoy a safe and truly gluten free diet. The use of the Society's gluten free logo should only be applied to foods with no gluten. Not as proposed by the offending article and our society's President to food with a low level of gluten.

Prior to the better understanding of coeliac disease, a low gluten diet was the treatment for our disease. This dangerous and ineffective treatment of a low gluten diet was as a result of the limits of the then medical level of knowledge of our disease. The medical profession still has a long way to go to understand coeliac disease, but one thing is beyond doubt is that a gluten free diet enables coeliacs to lead a normal healthy life. If the ability to detect gluten is improving with technological developments, The Coeliac Society should be lobbying for these improvements to benefit its members, not make it easier for commercial interests to contaminate our food with gluten.

There is no safe level of gluten for a coeliac. No proper refereed scientific study has yet, under controlled conditions over a number of years been able to monitor the risks of low level of gluten on coeliacs. It is likely a study of this type would be unethical, due to the risks to coeliacs of any gluten in their diet. It is far better to be safe than harm members of The Coeliac Society with ambiguous policies.

We are benefiting from improved technology that enables the detection of very low levels of gluten. These improvements in gluten detection technology should be used for the benefit of coeliacs not to harm or confuse them. Please preserve the integrity of the Society's logo, so we can be assured, it really means gluten free if we see our logo on a product. Thank you

*Terry O'Leary*

*B.App.Sc.(UNSW) and M.App.Sc. (UNSW)  
Coeliac Society member since 1997*

### Comments from Dr Jason Tye-Din and Dr Bob Anderson

Medical recommendations need to be based on best available evidence, with the health of patients taking priority. For people with coeliac disease, health considerations are paramount when it comes to determining if there is a level of gluten that can be safely consumed. More than a dozen studies, including randomised controlled trials (the type of trial considered to provide the best quality of evidence), have reassured us that small bowel inflammation, atrophy and activation of coeliac disease is not observed when less than 10mg of gluten is consumed daily by people with coeliac disease.

To actually reach this safely tolerated level of 10mg, one would have to eat half a kilogram (500g) of food containing 20 parts per million (ppm) of gluten. From a practical standpoint, this is very unlikely during the course of a normal day's food intake. Because of the available data supporting its safety, 20 ppm has been adopted as the standard for gluten free labelling by the International Codex Food Standard in Europe, the UK, and is also likely to be adopted in the United States.

Whilst appealing, adopting a standard lower than 20ppm restricts the commercial viability of many gluten free food products, further increasing cost and limiting food choices for coeliacs already following a restricted diet. Our view is that this would only be acceptable if there was a demonstrated medical need to consistently maintain content below 20ppm.

Since there is not, and the practical requirement to ensure gluten free food affordability and range is important for all coeliac sufferers, we support the decision of The Coeliac Society to aim to adopt 20ppm as the gluten free food labeling standard. This would also bring Australia in line with accepted international practice.

*Dr Jason Tye-Din*

*Consultant Gastroenterologist at the Royal Melbourne and Box Hill Hospitals; NHMRC post-doctoral researcher at the Walter and Elizer Hall Institute of Medical Research; Consultant and shareholder of Nexpep Pty Ltd; Chairman Clinical Advisory Committee, Coeliac Research Fund.*

*Dr Bob Anderson PhD FRACP*

*Founder and Chairman of the Board, Coeliac Research Fund; Lab Head, Water and Eliza Hall Institute, Melbourne, Australia; Gastroenterologist, Alfred Hospital, Melbourne; CEO, Director and Founder, Nexpep Pty Ltd*

### Comments from the US

I am a writer for *Gluten-Free Living*, a US magazine for those who follow the gluten free diet. I am writing about some of the international developments regarding gluten free labelling and have been reading about the topic in your most recent Australian Coeliac magazine.

Your article in the magazine says the Australian Coeliac Society is going to endorse products that contain less than 20 ppm of gluten even though these products cannot be labelled gluten free in your country because they do not meet the lowest detectable level standard.

Struggles over gluten free labelling surely know no boundaries. In the US, our Food and Drug Administration has not yet defined what the gluten free label means even though they were supposed to do so more than two years ago under labeling law. But 20 ppm has been proposed and many companies are meeting that standard even without any regulation. And we have certification programs by two coeliac groups that help consumers make informed decisions.

I very much enjoyed your article on labelling in Australia.

*Amy Ratner*

*Associate Editor / Gluten-Free Living*

The Society has recently heard that two of Australia's leading food manufacturers are removing the gluten free label from some products because of the increasing sensitivity of the testing method. With some products the gluten level is estimated to be as low as 1ppm.

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